Creating a Vision for Health Literacy’s Future: The Research Agenda

The 8th Annual Health Literacy Research Conference
Bethesda, Maryland
October 14, 2016
Today’s Agenda

Introduction
Michael Villaire 10 min

Panel Presentation 30 min
- Michael Villaire: Perceptions from the Field
- Cynthia Baur, Research Goals of the National Action Plan
- Rima Rudd, Paradigm Shift & Research Agenda

Research Ideas – Cynthia Baur 10 min
Cards:
- What priority question will drive new research?
- What research is needed to support efficacious practice and policy changes?

Open Mic – Michael Villaire 30 min
Focus: A Research Agenda for Work Ahead
- Priority question to drive new research (10 min)
- Research needed to support practice (10 min)
- Research needed to support policy (10 min)

Research Themes – Julie McKinney 10 min
Creating a Vision for Health Literacy’s Future: The Research Agenda

Michael Villaire, MSLM
CEO, The Institute for Healthcare Advancement (IHA)

The 8th Annual Health Literacy Research Conference
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Discussions in the Field

- **Purpose:** Outline a path forward

- **Guiding Questions First Asked of Practitioners:**
  - What are the opportunities for the HL community?
  - What are the challenges / barriers / gaps
  - What action can we take to meet the challenges, eliminate the barriers, fill the gaps?
  - It’s 2026 – What does success look like?
Activities to Date

- HL On-Line Discussion Group
- IHA Annual Health Literacy Conference Visioning
- Job Analysis Task Force – Health Literacy
- Now: HARC
Perspectives

- Practitioners
  - Medical Practice
  - Nursing
  - Dentistry
  - Health Education / Health Promotion
  - Developers of health materials, tools …

- Researchers

- Policy Makers
Two Fold Exchange

Research Findings → Practice

Practice Insights → New Research Questions

Policy Change → Research Findings
IHA Conference
Visioning Exercise

Needs

• Increased awareness of HL relevance & impact
• A business case for HL
• Equity among and between practitioners and researchers
• Education / professional development opportunities

Actions

• Collaborate & create new partnerships in and with communities
• Integrate HL in patient activation, decision making, and self-care
• Integrate HL insights into broader health communication efforts
Job Analysis Task Force

Needs
Establish a psychometrically sound and legally defensible foundation for a credential

Actions [under way]
- Document a competency framework
- Delineate practice domains
- Define key tasks and knowledge for those working in the health literacy field.
Research Contribution

What are your current research questions?
What research questions are being raised by practitioners?
How might answers re-shape or guide practice and policy?

To spur some thoughts:

Our next two panelists will offer an overview of the research agenda articulated in the 2010 National Action Plan and raise new issues precipitated by a shift in our concepts of health literacy.
Linking the National Action Plan and Visions for Health Literacy’s Future

Cynthia Baur, Ph.D.
Senior Advisor for Health Literacy

8th Annual Health Literacy Research Conference

October 13-14, 2016
National Action Plan to Improve Health Literacy

- U.S. Department of Health and Human Services (HHS) released plan in 2010
  - Seven broad goals
  - Multiple strategies for each goal
  - Many stakeholders involved
  - Public and private sector implementation

Tampa, Florida town hall 2008
Seven Goals

- Health information creation and dissemination
- Healthcare services
- Early childhood-university education
- Community-based services
- Partnership and collaboration
- Research and evaluation
- Dissemination of evidence-based practice
Research and Evaluation Goal

- Increase basic research and the development, implementation, and evaluation of practices and interventions to improve health literacy
  - Reflected and stimulated investment
    - NIH reports 536 projects with more than $500 million in funding, 2004-2015
      - https://obssr.od.nih.gov/literature-health-literacy-20-years-science-improve-knowledge-skills-health/
    - NIH and AHRQ support of conferences, including this conference
Where Were Gaps in 2010?

- General gaps
  - Root causes of (not associations with) limited health literacy
  - Theory and model-based research
  - Evaluation of existing interventions
- Methods
  - Community-based research
  - Population-based survey research
  - Systematic reviews
2010 Gaps in Specific Topic Research

- Numeracy and visual communication
- Measurement of individual and population skills
  - Including state, county, and neighborhood estimations
- Measurement of health professionals’ skills
- Economic and social costs of limited health literacy
- Technologies’ effects on limited health literacy
- Barriers and strategies to improve access and navigation
- Role of health literacy in high priority prevention and clinical activities
- Participation in clinical trials and other health research
- Utility of a health literacy scorecard
Overlap with Gaps Based on May 2016 IHA Visioning Activities

- Chronic diseases/prevention
- Community-based research
- Business case/costs
- Professional training
- Technologies
Discussion Question

Which topics remain under-researched and are they still priorities?
For more information, contact CDC
1-800-CDC-INFO (232-4636)

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.
Considering the Future: Health Literacy Research

We can’t really know what we don’t know … But we can consider:

- What are some unanswered questions?
- What haven’t we examined in sufficient detail?
- What are some of the unexplored areas?
- Are there any missing variables not yet considered or measured?
Expansion: Literacy Skills

Interaction & Dialogue

- Presentation skills
- Listening skills
- Language [shared and rare]
- Efficacy [interruptions, question asking]

Math

- Concepts
- Calculations
- Use of tools
Expansion: Analyses of Texts and Tasks

Examination of Texts and Analyses of Complexity
- Pilot testing
- Simplification
- Rigorous development

Examination of Tasks and Analyses of Difficulty
- Pilot testing
- Simplification
- Rigorous development

Development of Protocols & Regulations
Expansion: Analyses of Key Variables

Health Literacy as an interaction
- Reader & writer
- Listener & speaker
- Tools
- Tasks
- Contexts
- Expectations

Needed: Attention to
- Skills of health providers
- Complexity of materials
- Attributes of systems

RQ: Are there links between health outcomes and:
- Providers’ communication skills/abilities
- Accessibility of health information
- Quality of materials and tools & ease of use
- Attributes of health care environments, systems

Needed: Measures & Analyses of all key variables
Expansion: Broader Scope

Studies Beyond Health Care Settings

- Rights and Responsibilities
- Public Health
  - Public health postings and announcements
  - Presentation of data findings
  - Community participatory research and activation
  - Rights and responsibility
- Environmental Health
  - Nature of science: scientific methods, scientific findings
  - Legal literacy [regulations and procedures]
- Occupational Health
- Disaster Response, Mitigation, and Management
Expansion: Implementation Studies

Accessible Information
• RQ: Do such changes affect engagement? Decision making? Satisfaction? Health outcomes?

Rigorous ‘delivery’ of information
• RQ: Do changes affect engagement? Decision making? Satisfaction? Health outcomes?

Development of inclusive environments for respectful exchange and decision making
• RQ: What supports are needed?

Strengthening the literacy exchange through training programs/education efforts
• RQ: Do changes affect engagement? Decision making? Satisfaction? health outcomes?

Analyses of all key variables
Health Literacy as a Complex Interaction

- Full panoply of literacy skills
- All key players
- Variety of texts and tasks
- Interplay of variables
- Multiple contexts
- Efficacious change
Research Questions
(Your Reflections)

Research – Cynthia Baur (10 minutes)
Questions (answer on cards)
- What priority question will drive new research?
- What research is needed to support efficacious practice and policy changes?
Facilitated Discussion with Open Mic

Focus: A Research Agenda for Work Ahead
Michael Villaire

- Priorities question to drive new research
- Research needed to support practice
- Research needed to support policy change